

**Social Security Advisory Board  
Discussion Forum on the Definition of Disability**

**Talking Points**

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## **BACKGROUND**

### **1. Historical context.**

- The old paradigm of disability policy viewed people with disabilities as "defective" and in need of "fixing." Disability equated with "inability" and "dependency."
- The new paradigm of disability policy views physical, mental, and sensory impairments as natural and normal aspects of the human experience that in no way diminish a person's right to fully participate in all aspects of society, including working, commensurate with the person's abilities and capabilities. The new paradigm focuses on "fixing" the environment to ensure effective and meaningful opportunity to participate in the most integrated setting appropriate.

### **2. Goals of Disability Policy.**

- Equality of opportunity (individualization, meaningful and effective opportunity, most integrated setting appropriate).
- Full participation (self-determination, self-advocacy, real and informed choice).
- Independent living (legitimate outcome, skills, cash assistance, services and supports).
- Economic self-sufficiency (legitimate outcome, skills, cash assistance and work incentives, and tax incentives).

### **3. A Mix of Old and New Paradigms of Disability Policy in Federal SSDI and SSI Programs.**

- Current definition of initial eligibility for the SSDI and SSI programs is based on the old paradigm (equates disability with inability to work).
- Certain work incentives for SSI beneficiaries reflect new paradigm/goals (e.g., gradual reduction in benefits, continued attachment/supports).

- Basic approach in the SSDI program reflects the old paradigm i.e., if you work above a specified level (SGA) you are not disabled.
- Complexity and mixed signals confusing to beneficiaries.

#### **4. Goals and Purposes of the SSDI and SSI Programs.**

- What were the historical goals of the SSDI and SSI programs?
- What are the stated assumptions as to the future goals and purposes of the SSDI program and the SSI program? In other words, given the heterogeneity of the population, do the stated goals and purposes provide an adequate framework for the establishment of program policies that enable persons with significant disabilities to live in the community and work commensurate with their abilities and capabilities?
- What criteria and measurements should be used to evaluate whether the policies tested result in accomplishing the stated goals and purposes?

#### **5. Population Targeted by the SSDI and SSI programs.**

What assumptions are made regarding the heterogeneity of the population of SSDI and SSI beneficiaries?

- Proportion of beneficiaries who cannot work at all?
- Who can work but below SGA?
- Who can sustain work above SGA on a regular basis if work disincentives are removed or lowered and/or ongoing services and supports are made available?
- Who can sustain work above SGA on an intermittent basis given the episodic nature of the individual's disability if work disincentives are removed or lowered and/or ongoing services and supports are made available?
- What is the impact of age, education, and nature of work previously performed?
- What proportion has significant work experience prior to becoming disabled?
- What proportion will need substantial assistance in securing their first jobs?
- How many would have access to health care coverage if they did not receive SSDI or SSI?

#### **6. Relationship between the SSDI and SSI Programs.**

Given the significant number of concurrent beneficiaries under the SSDI and SSI programs, should efforts be made to make the two programs more compatible? If so, what efforts are appropriate?

## **7. Relationship between the SSDI and SSI Programs and other Federal, State, and Private Sector Return to Work Initiatives.**

- Need to break down program silos and facilitate comprehensive, person-centered approaches to addressing the multiplicity of needs facing persons with disabilities.
- Need to understand the relationship between the SSDI and SSI programs and:
  - Medicaid, vocational rehabilitation, WIA, Ticket to Work, housing, food programs, workers compensation, welfare reform, Medicaid Buy-In programs, benefits counseling, state SSI supplementation and
  - Private sector programs, e.g., short and long-term disability insurance.

## **NEW CONCEPTUAL FRAMEWORK FOR SSI AND SSDI PROGRAMS THAT REFLECTS THE NEW PARADIGM AND GOALS OF DISABILITY POLICY.**

### **1. Purpose:**

- Provide basic income on a regular or intermittent basis (as needed) to enable an individual with a significant disability (ongoing or episodic) to choose to live in the community.
- Provide for wage replacement based on an insurance concept of workers' contribution to an insurance pool to be drawn on in case of an onset of a significant disability.
- Provide income supplementation for persons with significant disabilities who need cash assistance to live in the community because their disability limits the amount of production and earnings they are able to generate.
- Provide income assistance to lessen the burden on the individual's family members related to the cost in time and funds to care for a person with significant disabilities that requires assistance to be able to live in the community.

**NOTE:** Given the heterogeneity of the population, these goals and purposes provide an adequate framework for the establishment of program policies that enable persons with significant disabilities to live in the community and work commensurate with their abilities and capabilities.

- ### **2. Definitions:**
- Include a definition for the term "person with a significant disability" using updated listings and improved functional assessments.

3. **Eligibility:** A person with a significant disability would be eligible for cash assistance if he/she needs such assistance on the basis of disability (ongoing or episodic) consistent with the purposes described above.
4. **Work incentives.** Work incentives for both the SSI and SSDI programs should include, but not be limited to, gradual rather than precipitous reduction in benefits as earnings increase, recognition of impairment-related work expenses, and enabling independence through asset accumulation.
5. **Continued Attachment to the Program:** Attachment to the SSI and SSDI programs should be maintained so long as person is still considered a person with a significant disability.
6. **Services and Supports Enabling Work.** Persons with significant disabilities must receive necessary health care (including long-term services and supports) and employment-related services and supports enabling work. Receipt of health care and employment-related services and supports for this population would not be tied to receipt of cash assistance under the SSDI or SSI program.

## REACTIONS TO DAVID STAPLETON'S PRESENTATION

### 1. Unwarranted Reliance on Inadequate Data Sources

- Stapleton uses CPS data, among other data sources, to describe so-called "facts" and "empirical evidence" and then relies, in part, on this data to draw cause and effect policy conclusions.
- According to Stapleton and his colleagues at Cornell this CPS data on which he relies is "inadequate" and has "significant limitations." Others, including the Census Bureau, describe significant limitations regarding the uses of the CPS data related to people with disabilities.
- According to standards used by GAO, when auditors are unable to obtain sufficiently valid and reliable data, they may find it necessary to use the data but clearly indicate the data's limitations and "refrain from making **unwarranted** conclusions and recommendations." [Emphasis added]
  - Using GAO standards, I believe it is unwarranted to use CPS data to draw the conclusion that the bleak economic picture "can be largely attributed to the conceptual definition of eligibility and no amount of tinkering with how that definition is implemented will make that picture significantly brighter."
  - Using GAO standards, I believe it is unwarranted to use CPS data to identify causes of the decline of the employment rate of persons with disabilities such as the ADA and the "liberalization"

of the SSDI eligibility rules in the 1980s and the gradual increase in the replacement rate.

## 2. Goals and Purposes.

- What are the goals and purposes of the self-support approach outlined by Stapleton?

## 3. Description (in regular font) and Analysis (in bold) of Core Components Of Self-Support Approach Proposed by Stapleton as Alternative to Current Policy.

- "Would need eligibility rules."
  - **Would these rules be objective or subjective (requiring a high degree of sophistication and expertise)?**
  - **Who would administer the eligibility rules?**
- First line eligibility rules-medical rules used to identify "people who face significant medical challenges" (that could result in inability to work if appropriate supports are not available).
  - **What criteria would be used to identify the protected class i.e., "people who face significant medical challenges"?**
  - **Who would make this determination?**
- "Actual engagement in work would be irrelevant."
  - **This has appeal for those with disabilities who would like to attempt to work. What does it mean for those who are not able to work?**
- "Most" who qualify would be "expected to work at some level" and would be provided with "employment support services."
  - **What criteria would be used to determine who is expected to work?**
  - **What criteria would be used to determine the expected level of work?**
  - **What happens when an individual's impairment is episodic?**
  - **What employment supports would be provided?**
  - **Who would make this determination?**

- Those "able" only to attain low-wage jobs or work limited hours could be offered, "wage subsidies" or "tax credits."
  - **What criteria would be used to determine who is "able" only to obtain low-wage jobs or work limited hours?**
  - **How would the amount of wage subsidies be determined?**
  - **How do wage subsidies differ from partial cash payments under SSI?**
  - **Who would benefit from tax credits? What level of credits?**
  - **Who would make these determinations?**
  
- Those with "the most severe conditions" would be provided with income support that would not be conditioned on earnings unless earnings were "very high."
  - **What criteria would be used to identify those "with the most severe conditions" who would be provided with income support?**
  - **What criteria would be used to condition income support based on "very high" income?**
  - **Who would make these determinations?**
  
- Those in the oldest age group (50+) might be given access to their retirement benefits on an actuarial fair basis, perhaps adjusted for the effect of their medical conditions on their life expectancy.
  - **Why 50+ given access to their retirement benefits?**
  - **The 50+ group is also a heterogeneous population. What happens for those who do not want early retirement?**
  - **What constitutes actuarial fair basis?**
  - **What criteria would be used to make adjustments for the effect of medical conditions on their life expectancy?**
  - **Would these folks be entitled to Medicare immediately?**
  - **Who would make these determinations?**
  
- Health insurance benefits designed for people with disabilities would be independent of work status and available for life but under certain conditions the beneficiary and/or the beneficiary's employer would be expected to pay a share of the cost.
  - **What criteria would be used to determine which people with disabilities would be entitled to health insurance benefits for life?**

- **What benefits would be provided-federal minimum benefit package or state-by-state determined benefits comparable to Medicaid?**
- **Who would make these determinations?**

#### **4. Significant Challenges Identified by Stapleton.**

- Can we afford such a program?
- Can we muster the resources from the multiplicity of independent public programs?
- How can a government bureaucracy effectively administer benefits that are tailored to the support needs of an extremely heterogeneous population?
- How can we avoid irreparably harming millions of those we intend to help as we transition to a new system and experiment with the new approach?

### **GUIDING PRINCIPLES FOR PURSUING REFORM.**

1. Overarching principle should be "do no harm."
2. Go slow. SSA should conduct appropriate studies, research and complete demonstrations before pursuing new legislation--need to understand the consequences and unintended consequences of change; need to understand costs and investigate the feasibility and practicality of any change (e.g., administrative capacity of SSA and state vocational rehabilitation agencies) and then determine whether change will be an improvement using agreed-upon criteria for measuring success.
3. Clearly identify the goals/purposes of an effort to reform the definition of disability (and initial eligibility) for the SSDI and SSI programs.
  - Is the purpose of the reform to update the program to reflect the new paradigm/goals of disability policy i.e., facilitate, not impede achieving equality of opportunity, full participation, independent living, and economic self-sufficiency? In other words, will the reform effort enable persons with significant disabilities to get the cash assistance and service and supports they need to live in the community and work, commensurate with their abilities and capabilities? [Note: this approach may result in additional costs initially but may result in longer-term savings as more persons earn higher salaries and pay taxes.]
  - Is the purpose of the reform to use the new paradigm as a subterfuge for restricting eligibility? In other words, is the goal to reduce/restrict costs by restricting eligibility?

4. Are the existing SSDI and SSI programs working for a significant percentage of current beneficiaries who cannot work or who are not likely to work above SGA? Should reforms revamp the entire program for all or provide a choice for those who are willing to risk working above SGA if provided with meaningful work incentives and necessary health care and ongoing services and supports? Would this voluntary approach be the best way to introduce these changes into the current system?
5. How does the reform make the SSI and SSDI programs more compatible?
6. How does the reform facilitate comprehensive, person-centered approaches and how does the reform relate to other federal, state, and private sector initiatives?